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ABSTRACT

This handbook is intended to assist policy boards and Interagency Coordinating Councils in developing and writing clear guidelines for implementing Part H of the Individuals with Disabilities Education Act which mandates early intervention services to infants and toddlers with disabilities. Principles are rooted in a "family systems" model of intervention which stresses respecting family autonomy, a collaborative mode of intervention, and a broad definition of "family." The first component of the guide describes the historical context of the law and the nature of the study of ethics. The next component is devoted to background information about the effectiveness of particular intervention strategies with different clienteles. A major section on ethical issues is divided into three sub-sections titled : "Child Centered," "Family Centered," and "Profession Centered." Because decision making often involves conflicts in values or assumptions, one component of the handbook deals with "Value Conflicts in a Group" with sections on "Change of Views" and "Problems of Self-Interest." The final component describes a set of procedures that are then applied to a scenario in which problems are identified, value conflicts are made salient, and solutions proposed. An annotated bibliography of 84 items and sample forms are appended. (DB)

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# HANDBOOK FOR ETHICAL POLICY MAKING

## NORTH CAROLINA INSTITUTE FOR POLICY STUDIES

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This handbook represents the work of many thoughtful minds and caring souls. The content has been drawn from papers written by several authors. The papers were commissioned by Dr. James J. Gallagher, Dr. James Paul and Dr. Bryant Kendrick in response to the need to provide guidelines for the policy-writing groups concerned with implementing Part H in IDEA. Dr. Gallagher wrote a paper dealing with the role of values and facts in policy development for handicapped infants and toddlers and their families. Dr. Paul's paper provided insights into the relationship of ethics and policy development. Dr. Rosemary Tong also contributed a paper dealing with ethics and policy-writing. In her paper, Dr. Ann Wilson discussed the problems of allocating resources relative to PL 101576 and the ethical foundations to be considered in decision-making. Dr. Kendrick's work on the ethical method for making decisions is the basis for the procedures and protocols generated for the last section of the handbook.

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As the final author, I drew on the experts' material and ideas to create a readable format for the handbook. Drafts of the handbook were reviewed by a number of experts including some of the original authors. Dr. Kendrick contributed the introduction to the section on ethical decision-making. Dr. Gallagher carefully edited the background sections. Dr. Paul provided constant supportive guidance for the various drafts. At the same time, Dr. Gallagher provided several reviewers and helpful critiques to make the handbook more appealing for both professionals and lay persons alike. Dr. Daphne Thomas shared her time and extensive knowledge of family systems with me, especially in the application portion of the last section of the book. Her encouragement and helpful suggestions for fleshing out the scenarios based on case histories are greatly appreciated. Merry Blount created the graphics used throughout the handbook and also designed the cover. Writing this handbook has been a rewarding task. I am grateful for having had the opportunity to be part of a project that has such potential for helping the children and their families who will be the benefactors of this legislation.

Jane F. Young
University of South Florida, 1992.

## HANDBOOK FOR ETHICAL POLICY MAKING

### Purpose of This Handbook

The purpose of this handbook is to provide appropriate information which can be used by policy boards for developing and writing clear guidelines for implementing Part H of IDEA in the PL 99-457 legislation. The intent of PL 99-457 is clear: *Infants and toddlers with disabilities and their families should receive the kind of help they need early enough to prevent or reduce the impact of the disabilities.* While that sounds straightforward enough, implementing the law to meet that intent is not easy. Unfortunately, scant resources imply limits. Such limits are sure to result in clashes of ideas, conflicts of values, and contests of assumptions. This handbook will identify some of the issues and provide stategies to help in resolving potential conflicts and making ethical policy decisions.

The content and the procedures outlined in this handbook are rooted in a "family systems" model of intervention that reflects a belief in the need to enable and empower families to deal successfully with situations that have the potential to generate stressful conditions. In a family systems model the child is seen as an integral part of family that should receive intervention services. The general tone of the handbook, the vignettes, and selected examples used in each of the components are congruent with the beliefs and values that underlie this model. Key assumptions of this model include a sense of respect for family autonomy, a collaborative mode of intervention, and a broad definition of what constitutes a "family". Such a definition is found in the *Report of the House Memorial 5 Task Force on Young Children and Families* (1990) in New Mexico:

> Families are big, small, extended,nuclear, multi-generational, with one parent, two parents, and grandparents. We live under

> one roof or many. A family can be as temporary as a few weeks,
> as permanent as forever. We become part of a family by birth,
> adoption, marriage, or a from a desire for mutual support. (p.1)

Potential conflicts lurk along the roads leading to formulating ethical policies in any field. For example, each state will have to determine what constitutes "disability". Does this designation apply only to those children whose disabilities are self evident such as hearing impaired, blind, cerebral palsy, fetal alcohol syndrome or Down syndrome? In most instances this designation would also apply to children who manifest significant developmental delay by the age of three. Such children would include some of those born to economically disadvantaged parents, many of whom themselves have one or more physical, psychological or economic problems. Babies having AIDS and who demonstrate developmental delay are also intended to be included.

Among the myriad of major decisions that will have to be made about how best to serve such children and their families are questions of how to assess disability, how to judge the appropriateness of treatment, and how to counsel families about treatment. There are consequences of the decisions made in assessing the child and family. For example, can the intervention be made without unduly disrupting the family? What intervention model should be used? Who should provide the intervention services?

How will these decisions be made, and who will make them? There are a number of difficult decisions about early intervention that will confront policy makers who struggle to forge a set of ethical policies for enacting Part H of IDEA in their home states. Lasting solutions to these questions are derived through a commitment to forthright discussion of differing viewpoints. This handbook is designed to help those discussions be fruitful ones. Consequently, a quick overview of the contents of this handbook is appropriate.

Some people like to work through a document from the first page to last. This handbook can be used that way. Others prefer to work back and forth through a book finding the particular chapters or components that they are most interested in or know the least about. Thus, the term "components' rather than "chapters" in this handbook is based on identifying material that is situation-specific. *Component* implies a *part of the whole* in which all the components make up the finished product. The components, however, can be arranged according to how the readers think and work.

One component in this handbook describes the historical context of the law and the nature of the study of ethics. Another component is devoted to background information about the effectiveness of particular intervention strategies with different clienteles.

As those who have experience with drafting policies or interpreting policies in ethical ways know, "ethical policies" is a deceptively simple phrase. Therefore this handbook separates the Ethical Issues component into sections with sub-headings -- Child Centered, Family-Centered, and Profession-Centered -- to assist in the planning for implementation of Part H in IDEA in PL 99-457.

The process of decision-making requires guidelines to help resolve conflicts in values or assumptions. The component of decision-making includes some mechanisms for clarifying values and assumptions within a group. We believe this definition and ensuing clarification of the process are essential. Often members of a group -- all of whom are well-intentioned people -- have very different assumptions about Part H and how it should be implemented. Firmly entrenched values and beliefs about children, handicapping conditions, the role of government, and notions about "individual rights versus the greater good" debate will be brought to the task of policy development. If these differences in value assumptions and ideas exist within a group and are not confronted in some systematic way, they can eventually undermine the whole decision-making process. To address this, the handbook contains a component dealing

with "Value Conflicts in a group" --with subheadings "Change of Views", and"Problems of Self-Interest". The final component describes a set of procedures that are then applied to a scenario in which problems are identified, value conflicts are made salient, and solutions proposed. Policy implications for this scenario are also examined.

The Inter-agency Coordinating Council for Part H in IDEA is a fine example of a meeting place for these issues to be discussed and resolved. We hope this material will especially benefit those decision making bodies.

Because this document is written as a handbook as opposed to a journal article or paper, references are not cited in the textual material of each component. At the end of the handbook there is an annotated bibliography offering some further reading suggestions for those who seek more depth of coverage than these materials provide. This handbook is intended to provide support in the negotiating their way through the complicated, value-laden issues related to the implementation of Part H in IDEA.

# HISTORICAL CONTEXT OF IDEA

This component discusses the historical background for PL 99-457, the assumptions on which it is based, the current context for enacting the law and the groups which will be most involved in that process.

## Historical Background

PART H did not arise spontaneously from a few remarkable insights of the United States Congress. It is the most recent of a wide array of laws that reflect a deepening sensitivity to important social issues concerning vulnerable persons in our society.

Part H can trace its legacy to probably the most well-known of the all the legislation in this area which is PL 94-142 (The Education for All Handicapped Children Act) which guarantees the right of all children with special needs to be provided a free and appropriate education in the least restrictive environment. Over the years Congress has sought to address bias in psychological and educational tests, establish guidelines for due process ensuring that children with disabilities are not excluded from appropriate services, recognize the uniqueness and importance of the family, and guarantee parents the right to participate in decisions about the services their children should receive. Addressing these biases represents solid commitments in federal law and policy, commitments such as reassuring Hispanic parents whose children, because of language difficulty, test below their ability levels on standardized tests, or coping with the over-representation of African-American in programs for educable children with mental delays. These laws also give new hope to parents whose children with neurological impairment might not have received services in earlier times.

Part H continues this legacy of an increasingly inclusive perspective by acknowledging that most children with disabilities are denied a fair start in life long before they reach

kindergarten. Part H recognizes the importance of early intervention, despite the complexities that will surround the provision of such services. An important feature of Part H is that it contains a *discretionary provision* that supports preventive intervention for children with demonstrated developmental delay.

Assumptions underlying IDEA

The assumptions on which this law is based are inferred partly from research and partly from professional practice. Generally, assumptions tend to be implicit rather than explicit. If they remain implicit, such assumptions can be troublesome. The assumptions are reviewed briefly here because they may raise ethical issues for policy-making groups to deal with. Confronting these assumptions is important if the communication among group members is going to be unambiguous.

One major assumption is:

*In general, when it comes to intervention: the earlier the better.*

Might there be occasions when earlier is not necessarily better? Can the intervention be so early that it causes problems that could eventually right themselves? Research is not conclusive on earlier being better, but most professionals agree that the weight of evidence clearly supports the belief that the earlier the intervention, the better the results.

A second assumption acts a general rationale for the law:

*If help is not available to those infants and toddlers who need it, society will bear the costs of deficits that might have been remedied or ameliorated.*

The basis for this assumption is there are many conditions identified in the first 36 months of the child's life that can cause developmental delay. If, through intervention, the known delay becomes less debilitating, or the anticipated delay is precluded, then the intervention will be considered successful.

This assumption is troublesome because we should be providing such help because infants and toddlers need it -- not because these children may become an financial burden on us later in life. Many professionals consider the notion of cost-effectiveness to be irrelevant in the context of working with children with disabilities. Often, however, such difficult questions must be addressed when dealing with legislative bodies or the public.

The next assumption, based on Hippocrates' famous oath, reflects a common concern of those who work within the family systems framework:

*The intervention should do no harm!*

The "do no harm" principle might be viewed as being too obvious to warrant mentioning, but professionals in human services consider it to be one of the most critical principles of practice. It is possible to become so enthusiastic and so narrowly focused on the potentially positive results of a proposed intervention, that the larger picture is forgotten.

This leads logically to the next assumption:

*Parental and family involvement are important in developing plans for the child.*

Interventions that will be helpful and constructive are more likely if parents are involved from the beginning and the whole family unit is considered. The family systems model provides some different ways of thinking about how to work with the child very early in life within the family context. The family systems model is an all-encompassing way of recognizing that the "target" child is viewed as integral to the family's day to day existence as opposed to a "problem" component of the family. The family then becomes the focus of support. This is a very different way of "intervening" than when the exclusive focus is on the child's problem.

Finally, we have an assumption that is often stated as a principle in most books on child development:

*Development is a continuous process.*

However, life is not that simple -- at least not for all children who might be candidates for services provided by Part H in IDEA. Development may be "continuous" for some children but not necessarily "steady". In some situations development can be delayed for weeks, months, or even years depending on the specific disability.

Current Context and Groups Involved

Policy-writers, in an era of fluctuating economies and soaring health care costs, will be asked to account for the dollars spent to implement Part H. This is a challenge that may require a more thoughtful approach to the task than we might use in times of plenty.

A further challenge is presented by the number and diversity of professional groups that may be required to plan and deliver services. Several professional groups will be involved in providing services, specifically: Audiology, Medicine, Nursing, Nutrition, Occupational Therapy, Physical Therapy, Psychology, Social Work, Special Education and Speech and Language Pathology. Each of these has developed and advocates its own professional standards and definition of quality care. To date, no consistent strategy has emerged that would facilitate the integration of knowledge bases and philosophies across disciplines.

Undoubtedly, the debates ensuing from efforts to write ethical policies to implement PL 99-457 will provide an impetus for integration -- something that has been lacking in the past. One of the potential benefits of this law is the opportunity for talented and committed professionals to talk with one another about common goals and professional heritages. A positive outcome of the law is likely to be an enhanced appreciation of expertise, standards and professional practice across many disciplines.

Unfortunately, common goals do not necessarily lead to common agendas! The task of reaching accord on short and long-term objectives to achieve common goals is likely to generate lively conversation--perhaps even some heated arguments. Vested interests and self

interest are real hurdles for policy-writing groups. Such interests are often well-intended but can be counter-productive.

For example, a group might include one or more parents of Down Syndrome children, or a member who is a widely known expert on cerebral palsy. While it does not necessarily follow that these or any other members with "special interests" will advocate only policies that will primarily serve their own ends, that does sometimes happen. Uncontrolled self-interest on the part of an individual or portion of the group can work against a balanced group perspective. The component on **Ethical Issues Confronting Policy Makers**, beginning on page 17 provides practical suggestions for working through some of these problems. By frequently identifying special interests, a group can concentrate on the task of writing policies that benefit all candidates for service.

Today, we are much better informed than a decade ago about what can be done to help parents and children whose special needs preclude normal growth and development. There has been a great deal of helpful research in the last decade and consequently, interventions are now grounded in an expanded knowledge base. (The knowledge base is discussed in greater depth in the component on **Intervention Information**.)

The new law is another step taken by the nation toward closing the gap between what we are as a society and what we aspire to be. We aspire to be a nation that cares; to educate all our children for productive citizenry. We develop laws and policies to help us reach these ends in a fair and just manner.

## INTERVENTION INFORMATION

This component is intended to provide background information for those who may be unfamiliar with the research findings on early intervention. It is not an extensive review of the research, but it illustrates the constellation of variables that must be considered in developing early intervention strategies. Those professionals who are experts in early intervention practices, or who have a great deal of experience in writing policies to implement legislation in this area may want to move on to the next component on page 17.

### Types of Prevention

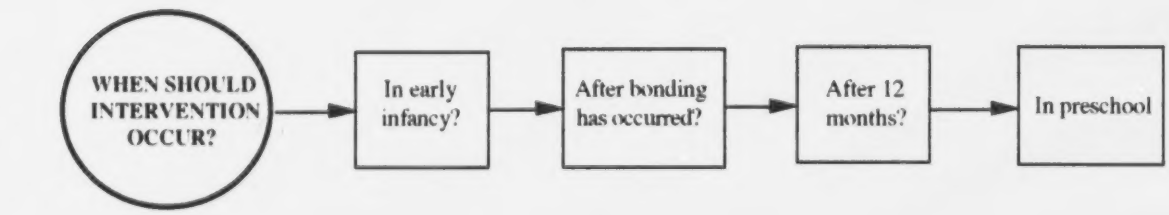
Intervention efforts aimed at preventing handicapping conditions can be categorized as Primary, Secondary, or Tertiary. *Primary* intervention consists of actions made in an attempt to prevent the condition from occurring in the first place. An example of primary intervention is improving the amount and frequency of prenatal care available to young poor teenage mothers whose babies are often identified as being "at risk". *Secondary* intervention takes place after the handicapping condition has been identified -- but before the worst of the consequences of such conditions are realized. An example of secondary intervention is providing help for a low birth-weight child, or a family with a low birth-weight baby. *Tertiary* intervention occurs when the condition has continued long enough for some of the serious consequences to arise, but while the condition can still be ameliorated to some degree. For example, the low birth-weight baby who did not receive secondary intervention might be identified at the day-care center as a child who needs special help to aid the developmental processes.

Figure 1 (see below) shows some of the critical decision points or intervention periods. One of the underlying assumptions of PL 99-457 is that the earlier the intervention is started, the more beneficial it will be for the baby and the family. This assumption does not take into

account the "self-righting" tendency of many babies. It appears that even infants who are born into environments that are less than wholly nurturing may manifest this "self-righting tendency" -- they are able to make adaptations to that environment during their early development. The most favorable intervention from birth to one year of age may not be with the child directly, but with the family and their special needs in caring for the child.

The degree of departure from the normal developmental pattern must be considered when determining when to intervene. Minor deviations observed during the first few months of life do not necessarily signal future limitations. There are many children who start life as premature babies in whom no developmental differences are obvious after several months or years.

Figure 1: Stages of intervention



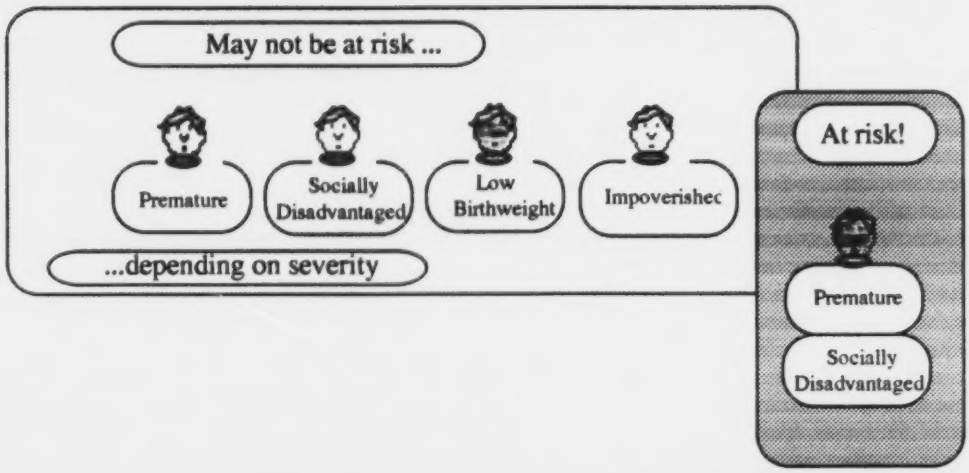

## Assessing Developmental Problems

There is still controversy about when neuromotor or intelligence assessments should take place and how they should be conducted. The problems of appropriate and accurate assessment are more complicated when the baby is premature or ill. Development can be affected by illness because the energy needed to develop normally is used to combat the effects

of the illness or prematurity. This is particularly noticeable in very low birth-weight babies (less than 1,000 grams). Currently, these babies have been considered "at risk" and it has seemed only logical to assume that they would encounter some developmental delays. With the exception of a very low birth-weight--less than two pounds-- it seems that the condition of either low birth-weight *or* prematurity is insufficient to label child "at risk" given the current state of knowledge.

Figure 2 on page 13 indicates that any single factor poses less of a risk for developmental delay than multiple factors and the interaction among those factors. Studies of premature babies who are born to impoverished families show that, many times, they simply do not do as well as similar babies born to less stressed families. On the other hand, premature babies who are reared in families that receive some social support may develop at a more expected developmental rate. Also, prematurity and/or low birthweight are conditions that probably warrant some intervention, especially when coupled with low socio-economic status.

Figure 2: Development assessment factors




To summarize, biological risk factors alone are less of a threat to development than are psychological risk factors, such as an alcoholic parent coupled with a lack of emotional nurturing. It has been suggested that the *number* and *severity* of factors, rather than any particular type of factors (biological or psychological), are the better predictors of developmental problems.

## Determining the Need for and Nature of the Intervention

The primary purpose of early intervention is to provide services that enable optimal development for all infants--regardless of the circumstances of their births. What must be reconciled with the implementation of this legislation is *what* kind of intervention is needed, *when* it is needed, *how* it can be provided such that it meets the baby's needs and meshes constructively with the family's lifestyle, and *at what cost*?

The ethical basis for cost benefit arguments may be questioned because of the implication that the value and quality of a human life can be determined by financial resources required to maintain it. Professionals in this field of work, therefore, are generally more comfortable in using the *quality of life* outcomes for assessing the appropriateness and timeliness of the intervention. For example, should the condition of a child born with AIDS be treated aggressively? Or, given our current knowledge of AIDS, should the child simply be allowed to live as normal a life as possible?

We might ask, what parallels can be been drawn with the "triage model" of treatment, a common medical practice. In triage, whoever is in charge has to decide which patients have priority for medical treatment. A goal of triage is to ensure that those persons who will die without immediate treatment will receive appropriate medical attention. The less severely injured are treated later.

## A Family Systems Model of Intervention

Current intervention strategies usually follow a family systems approach. In such an approach, the intervention strategies are child-focused but family-centered. The needs assessment generally centers on what help the *family* needs to care for the child. The family situation is carefully examined and family members have a say in what help they believe they need to increase their ability to take care of the child. This is very different from a model in which the intervention is aimed only at helping the child overcome specific difficulties, with less regard being paid to either the potential strengths inherent in the family structure, or the impact of the planned intervention on the family.

In a family systems model, the child is not viewed as an isolated individual but as an integral part of a family -- an organism that continues to develop and change in response to shifting conditions. In such a model, the family's structural integrity and its role in decision-making are held paramount. Professionals whose work is rooted in this model find

themselves sometimes moving in and out of the intervention mode as the family changes in its ability to manage the situation. The family of a child who is born with cerebral palsy may not need much help for the first few months of the baby's life. As the baby grows, however, the parents may need more assistance with care; or they may need some help with maintaining their relationship with each other or their relationship with the other siblings. In a family systems model the intervention operates within the context of the family's needs without forfeiting the welfare of the child who is the candidate for intervention. In this model, everyone's needs are factored into the decisions about when to intervene and what kinds of intervention will be the most helpful.

The Yale Child Welfare Program (Seitz, Rosenbaum & Apfel, 1985) showed just how effective a family systems approach to intervention could be. In this study, target families -- who had been evaluated as needing social services -- received the services of a home visitor (usually a social worker), a pediatrician, a primary day care worker and a developmental expert. The size and make-up of the team meant that in case of need, one of them was available to the family at all times. Intervention began during the mother's pregnancy and continued until the baby was two and a half years old. The mother received help with nutrition, feeding, and healthful living information. In addition, families were helped to understand the importance of developmental play activities and to exhibit positive behaviors toward the baby. Although the intervention did not have a lasting effect on the I.Q. score, these children had much better school attendance and needed less special education than children who had not received similar services. Unexpectedly, other family members who received this special support required considerably less public financial support for welfare and special education services. In other words, there was a benefit to the entire family from such services.

Of course not all types of interventions have documented support in the professional literature. For example, evidence is lacking to support the notion that there are any long-term

benefits of helping parents learn to "position" their babies exhibiting marked spasticity. Costs for such intervention would be hard to defend in cost-benefit discussions.

Issues relating to the timing of the intervention, or when should intervention occur, speak to "the earlier the better" assumption. Labelling a baby as being "at risk" too early may cause parents unnecessary anxiety. We have evidence that some babies are amazingly resilient; some babies manage to overcome environmental hazards and develop normally. The line is very fine between letting parents know that there is a possibility that their child may suffer from developmental delays for which there is help, and contributing to parents' anxiety such that it may negatively affect their interaction with the new baby.

In reference to timing, one critical measure of the need or perceived value of the intervention, however, is *what harm may prevail if there is no intervention?* If we can assume that by **not** providing early services, the quality of life for either the child or the family -- or both -- will worsen, then the answer is obvious; the earlier the better. On the other hand, if there is little likelihood of improving the baby's condition until she or he reaches school age, perhaps the available resources should be used for those children who will clearly benefit more immediately. The solution might be to determine the optimal age for intervention rather than to try to establish what harm would prevail if intervention is withheld.

Development does not follow a totally predictable course. It is a process of complex interactions among the baby, the parents, siblings and other significant adults. The social context in which development occurs cannot be ignored by trying to fit categories of services to categories of children or families. Professionals are in general agreement that panaceas do not exist. The Annotated Bibliography at the end of the handbook offers some further documentation on development and appropriate types of intervention strategies.

## ETHICAL ISSUES CONFRONTING POLICY MAKERS

In this component, concerning ethical issues that policy-making groups will have to deal with as they formulate reasonable policies, there are three major categories of issues:

1. Child-centered issues
2. Family-centered issues
3. Profession-centered issues.

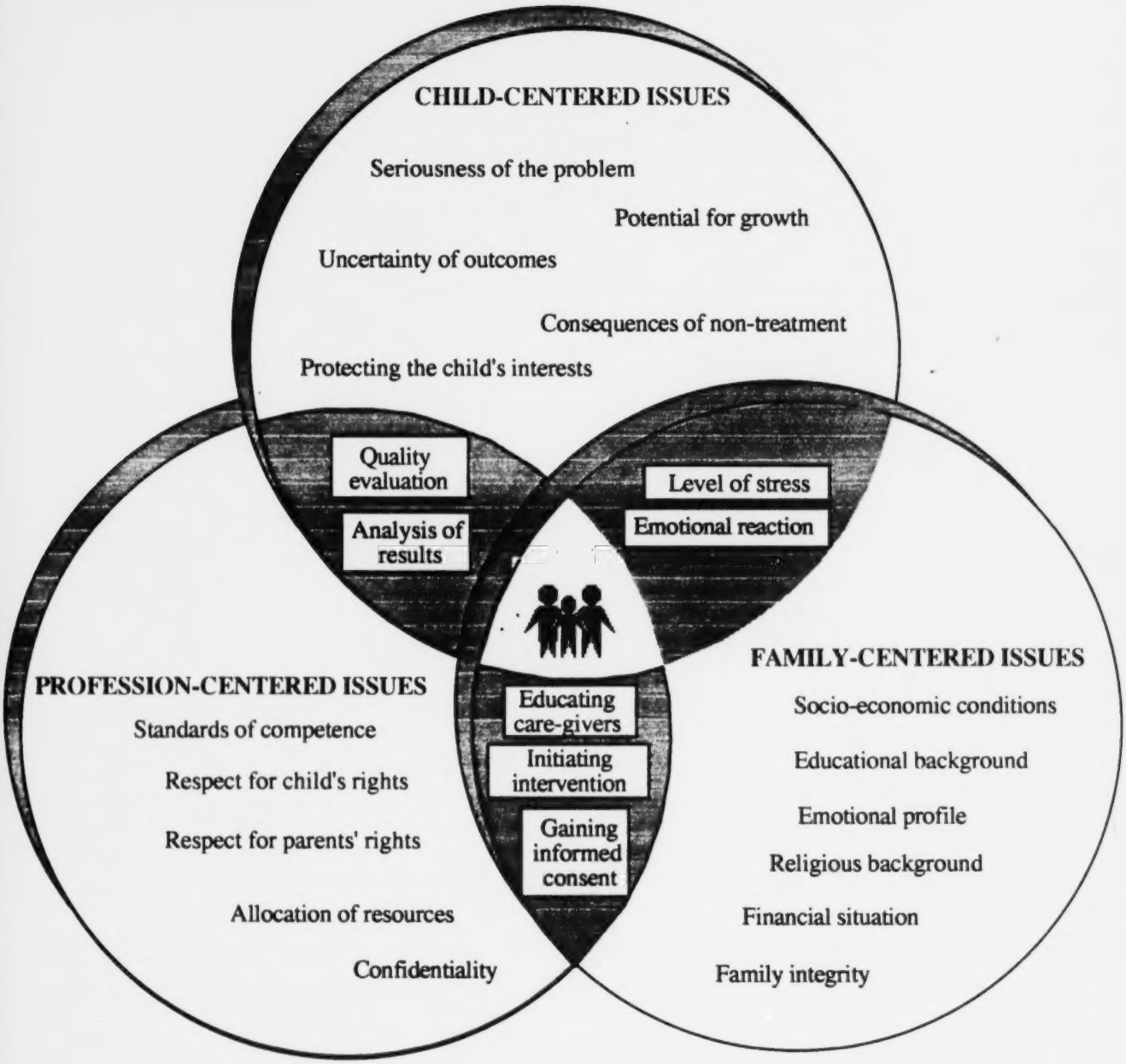
These three issues are not completely independent. They overlap and compete with one another. The chart on the following page visually displays some of that complexity and inter-relatedness. In reality, the issues cannot be separated from one another, nor will the solutions in one state necessarily work in another state. The autonomy granted states in Part H in IDEA is designed to allow each state to make decisions based on current conditions and priorities. Finally, the identification of the issues in this section does not imply order of importance. Only individual policy-making groups can determine which issues are critical to deal with first and which can be resolved later.

### Child-Centered Issues

#### The child in the context of the family.

Today's "family" is far more diverse than the family of 100 years ago. Today a family might include a lone father and children, or a single mother and child, both parents - one at a time - in a joint custody arrangement, grandparents as surrogate parents, aunts taking care of nephews and nieces, a foster family, a homosexual parent and his or her companion with one or more children, or two biological parents and their children. Whatever the arrangement, in all but the extreme situations, most children who are candidates for early intervention must depend on the parent or parent-substitute to initiate such intervention. (See Figure 3 on page 18.)

Figure 3. Interaction of Issues




**Interaction of Issues**

If the child is living with both biological or adoptive parents, discussions about the possibilities of intervention may be easier to initiate by the professionals . If the child is not living with his/her natural, or adoptive, parents that communication is probably going to require more effort. In cases where the parents' beliefs or child-rearing may be of concern related to neglect or abuse, the child could become a Ward of the Court and the responsibility for making intervention decisions will be removed from the parents altogether. Each one of these scenarios presents different issues and problems. Who will be the logical (and more importantly the most helpful) person or agency to initiate the discussion? The family? The doctor? A social worker? A counselor? A pastor?

In the previous component, the family systems model was identified as the model of choice for this handbook. In current professional practice this model is highly regarded as the most appropriate way to work with families who face a future with a child who may have one or more handicapping conditions. In essence, subscribers to this model see the family as an ever-changing -- perhaps evolutionary -- "system". In such a system, needs will vary according to how the needs of different family members vary over time. Accordingly, the service system will need to have different entry points to accommodate the variation in the presentation of the developmental delay.

For example, imagine a baby born with Down Syndrome that was not detected before birth. The parents, although they may be devastated, at first decline any intervention. Later when the child is about four and a half months old, they could begin to realize that the child might benefit from some form of intervention and seek assistance. This is a case in which the family initiates the intervention based on their needs.

While it is possible that the individual professionals involved might have been more forceful about seeing that the child received immediate help, the family systems model attempts to hold family integrity paramount. Family systems advocates would argue that, even if the

baby might benefit from earlier intervention, the pressure on the family to accept unwanted assistance could create such tension within the family that the baby's welfare, or the family integrity, or both, could be jeopardized. Family systems proponents believe that a critical feature of the systems model is to try to identify *when* the family might need and want help, and, alternatively, when such help has the potential to become a hindrance. They would also subscribe to the belief that *all* intervention avenues should be explored so that the family would have several plausible options.

On the other hand, suppose a baby born with the same syndrome had parents who continued to delay confronting reality. What should happen then? Is this neglect? Should someone, or some agency have intervened anyway? These are some of the problems facing policy groups as they begin to forge the policies for enacting this law.

What rights does the child have?

In the context of Part H in IDEA, the rights of children are ensured by the one over-arching safeguard; that is the right to receive appropriate quality treatment in a timely manner. Where intervention is deemed necessary, that intervention should be carried out as humanely as possible and in ways that exhibit respect for all concerned. Once permission is given for the child to receive early intervention, whose job is it to ensure that this is really what is best for the child? For example, think about a language-delayed three year-old who is receiving thirty minutes of language stimulation a week in a day-care setting. Is this really the "best" treatment? Or is it just the most convenient for the therapist? Or is it the only treatment available? Some one will have to play the Ombudsman role for that youngster to see that the "best" is really the *best*, as opposed to the most *expedient*.. Since young children can neither request nor refuse intervention, providing safeguards to ensure that neither they and their families are exploited nor short-changed should be embedded in the implementation policies.

Direct or Indirect Intervention?

One of the questions for policy groups will be to decide the degree to which policies will encompass both direct and indirect intervention. Direct intervention is usually focused on the child. A more indirect approach occurs when the family is the focus of the intervention. In such a case, the *family* would be given the necessary support to meet the *child's* needs. Professionals involved in indirect intervention would probably establish some procedures to allow frequent monitoring of the child's development as a means of judging whether the family needs more support.

There is some documentation that some chronically ill children with disabling conditions are at risk for abuse or neglect. It is hard for some parents to accept the idea that their child is not exactly what they expected. After all, it is *their* child! What could have gone wrong? Whose *fault* is it? Helping such parents deal with the situation rather than find fault (even if they may have precipitated it through consumption of drugs or alcohol) constitutes an intervention in itself. This is a form of **indirect** intervention. The position of the writers of this handbook is that the child's needs are evaluated within the context of the family strengths and needs. It is probable that both kinds of intervention will be used at various times for families with children considered "at risk".

## Family-Centered Issues

Problems can arise when the parents feel that they are contributing less to their baby's growth and development than are the experts who are working with them. Parental self-efficacy is a hallmark of healthy families but, in the current ethos of deferring to experts, it could be tempting for families to abrogate their decision-making power in favor of those people whom they perceive as having more expertise. This section deals with those issues that lie at the heart of the difficulties that families experience.

Identifying family needs.

Policy groups will have to be concerned with who should identify family needs. Sometimes the family will identify the needs, sometimes it will be the professionals. Once needs are identified, will there be any guidelines written for prioritizing them? What needs fall within the parameters of Part H? Who decides *what* the family needs to function successfully? Does the family need emotional support? Do they need help with finances? Does the family recognize what resources they have, and what resources are required, to meet this new challenge? Might the family need help with managing the resources they already have? Does the family even recognize a need for early intervention? Writing policies so that family integrity is preserved, and at the same time children are not held hostage to their families' lack of understanding of the condition, is not always easy.

Recognizing or acknowledging disability is sometimes hard for parents. Frequently, they are quite unprepared for the birth of a child with one or more disabling conditions. This is more probable when the parents are young and/or lack much formal education. Mothers who have had consistent prenatal care may have been alerted to possible (or definite) neonatal problems through sonograms or similar tests. Poorer parents, especially single young mothers, are rarely so well informed simply because they often lack appropriate prenatal care. Consequently, the miracle of the birth is tarnished by discovery that the baby is not "normal". Even if they are accepting of the baby's condition at birth, few new parents are aware of the potential economic demands that some special needs children place on the family.

How will the policies impact families with babies whose developmental delays are not immediately apparent -- who seem quite healthy at birth but show signs of delay or potential problems as they grow and develop? Again, educated parents with financial resources are likely to be alerted to the problem early, through frequent contact with pediatricians or preschool teachers. Impoverished and isolated mothers who do not use the public services

available may not have as much contact with professionals such as public health nurses. Consequently, the child's potential problems may not be recognized quickly enough for appropriate intervention to occur in a timely way. Regardless of economic background, parents may need help in learning to set aside time to provide the baby with enrichment or remedial exercises that will reduce the developmental delays. They may also need help in managing their time to accommodate the new tasks of working with their developmentally delayed child.

How Will the Intervention Affect the Family?

Early intervention is a positive step for the child who needs it. At the same time, questions will arise concerning what stresses will this intervention bring to the family unit? Will it make the parents or siblings more resentful of the child? Will the professional need to educate the parents about the child's needs and treatment? How will the family's right to raise their child as they see fit conflict with what the professionals believe is in the child's best interest? Will there be some severe financial drain on the family resources, so that the welfare of other children in the family might be negatively impacted?

Given information and support, often parents can begin to take greater control of the intervention schedule and activities. In some cases, it may be that they need some assistance for a few months when the child is first born. When they have a good handle on care-taking practices, they may be able to manage on their own for a year or two before help will be needed again -- perhaps different kinds of help. As stated earlier, the intervention should be seen as part of a total system rather than focused solely on the child.

What are the Family's Rights?

Advocates of the family systems model agree that parents' rights need to be recognized and that informed consent needs to be held paramount. For example, parents of a child who needs treatment have a right to know what their baby is facing, given the current state of

knowledge. They also have the right to know what an intervention may or may not do for the baby, and how it might affect the family as a whole. They have a right to learn about alternative treatments. This means that professionals must be very straightforward about the possible outcomes of the suggested treatment, versus the possible, or merely "hoped for", outcomes. Parents need to know what the intervention *will not* do.

It is usually impossible to guarantee treatment outcomes of early intervention, but professionals involved must be prepared to spend a great deal of time helping parents understand the nature and prognosis of the condition and proposed treatments. Truly informed consent is necessary for parents to make knowledgeable decisions regarding the baby's welfare. Parents may be more enthusiastic about inconvenient treatment times or intrusive measures if they understand what the intervention will do for their baby. In addition, the information should help parents better assess the new responsibilities required by the intervention.

Parents who have strong religious convictions that conflict with a particular intervention have the right to argue those convictions. Such conflicts will need to be resolved, and the number and nature of those conflicts will depend on the religious communities that are present in a state or region. There are numerous precedents for judicial intervention in cases where parents withhold medical treatment in life-threatening situations. It may be much harder to press for similar judicial intervention when it comes to enacting Part H in instances where the child's life is not at issue. Parents who are asked to suspend their religious convictions -- even temporarily -- may need much more intensive attention than parents who do not suffer such conflicts. This is especially likely if the baby is not showing much progress.

Parents also have the right to be properly trained if they are to provide some or most of the intervention. They have the right to have time to take care of their other children. The

rights of the infant or toddler needing intervention must be balanced with the rights of the rest of the family to have their needs met.

Families have a right to confidentiality. The assumption of confidentiality is a standard for professional care in any discipline. In early intervention cases, however, more care may be required because frequently it is not just one doctor who has access to the record; often several professional agencies are involved. In one instance, a mother talked about her husband's lack of acceptance of their special needs child, assuming that this information would be confidential. Later during an Individual Family Service Plan(IFSP) meeting, in which the father took part, this discussion was brought to light. The father was furious and the family unit suffered as a result of the professional's false assumption. The possibility for similar inadvertent losses of confidentiality may exist unless safeguards are written into the policies. Deciding what information may be revealed, or when and to whom it may be revealed are important policy issues. Finally, policies should provide clear guidelines about who is responsible for keeping official records.

Where Should the Intervention Take Place?

The answer to this question depends on the nature of the intervention. If the intervention has to be center-based because the therapeutic equipment must be housed there, or the center provides the optimal environment for the therapy, the question is a moot one. Center-based intervention can cause logistical problems for families who have limited transportation. Center-based treatment also can increase the risk of communicable disease, which can neutralize the positive effects of the therapy. In one instance, a child with a pronounced neuromuscular disorder was treated at a center. Unfortunately, he was frequently ill with pneumonia resulting from making the journey to the center. The therapist began to treat him at home, and although his progress was slower, he remained healthier. Sound policies for follow-up procedures will be important.

How Will the Challenge of Cultural Diversity be Met?

Working with parents and children who come from cultures which differ from that of the professionals' requires special planning. Such families are likely to need help with language. They may need the baby's problems explained to them in their native language. The proposed interventions and treatment may appear strange -- even bizarre -- to them, so good communication with these parents is very important . In some cultures, certain handicapping conditions are viewed more negatively than in other cultures. Child-rearing practices and religious beliefs may be different. In such instances, professionals will have to work hard to induce parents to make the time and effort necessary for the treatment. All the issues discussed previously in the handbook will apply to the culturally different family.

Who Will Pay the Piper?

Decisions about who should get which services, who should get them first, and how much money will be devoted to treatment, may be different across states. In some states those decisions will be made at the state level. Elsewhere, they might be made at the county or community level. Regardless of where the decisions are made, when it comes to implementing Part H in IDEA, the financial condition of the family will probably be one of the factors determining the services provided for the child and family. For example, if poverty is a major criterion for determining need for services, what happens to middle-class parents who were managing quite well financially until their special needs child came along? Now they will be in a financial bind if they have to pay for services which other families will receive free. Many middle-class families attain financial security through both parents' employment. Such a family would be hard-pressed to maintain its economic sufficiency if one parent has to quit work to take care of the baby with special needs. Will this family have to descend to some level of economic deprivation to receive services, or will they be able to pay on a sliding scale? Will treatment availability depend on the intensity of service that a child needs? These are

tough questions that need to be addressed in financially tough times. Sound policies will establish reasonable and ethical parameters for determining eligibility for receiving services such that those children who really need the services will get them.

A related problem may be: can families be required to pay for services that they are averse to? Obviously, one answer is that every effort would be made to persuade the family to agree that the service *is* desirable -- perhaps vital -- to the child's well-being. If, despite such an effort, the family is reluctant to expend its resources on services, what recourse will professionals have to ensure that the economically favored family will pay a "fair share"? Will services be denied to a youngster whose parents are financially able to pay for services but choose not to?

## Profession-Centered Issues

### Professional Competence and Standards.

Successful enactment of Part H is predicated upon the professional competence and sound standards of practice within the professional groups. Professional competence is described as knowing how to determine *what* intervention is necessary with *which* children and at *what intensity*, when to start, and when to stop. Professional competence means keeping abreast of the current research on interventions and treatments, so that state of the art services can be provided. Good professional practice involves knowing how to talk with parents -- and how to listen. Good professional practice includes developing procedures for family involvement, preparing family members for what lies ahead and, if necessary, helping them acquire the skills needed to care for their baby or toddler in positive ways.

Good professional practice may also mean going to bat for the family or the child in those cases where one or the other is in conflict with the system. David, who was dying of a special form of muscular dystrophy, is a good example. David loved preschool and, despite the fact that he did not have much time left, he participated as fully as possible in the activities.

The special relationships he enjoyed with the other children seemed to make life bearable. His participation, however, called for more attention from the teachers than did that of the other children. The preschool director, faced with budget difficulties and stated concern from parents who felt their children would get more attention if David's needs were not so great, wanted to "discontinue" David. The teacher argued on David's behalf and eventually persuaded the director that David was owed this chance to "live until he died". It is conceivable that this issue is one that will become more frequent as more and more children diagnosed as having AIDS and similar diseases with poor prognoses attend preschools or day-care centers.

Good professional practice can be described as ensuring that professional standards are maintained at all times--even if it means some children have to wait for services. It means knowing where to draw the line between adequate "make-shift" services that can be devised in creative ways, and poor, or counter-productive, services resulting from lack of trained personnel. Professionals also use appropriate language when talking about children with special needs , and they protect the confidentiality of information about their clients. Good professional practice includes being able to develop a first rate IFSP and knowing how to carry it out.

Philosophy of Care.

Good professional practice is based on sound philosophies. Professionals must face many difficult questions and should have a well-considered and reasoned perspective to guide their practice. Many questions cannot be answered with logic or science; they are questions about values and preferences. For example:

* "Is institutionalization ever warranted?"
* "What do I believe about the use of technology over the 'soft touch' approach of strictly human intervention?"

* "How do I feel about parents who put their religious convictions before their baby's welfare?"
* "How do I deal with a substance-abusing pregnant teen?"
* "How will I deal with parents like this?"
* "Am I willing to refer this baby to another professional whose expertise may be better suited to the condition, or do I believe that my rapport with the parents and the baby should be held paramount?"
* "Need this really be a conflict?"

Ego, personal values, and self interests of professionals are often involved in answering questions like these. Those persons developing public policy have a particularly difficult challenge in protecting the values and preferences of families on the one hand, and the legitimate interests of professionals on the other.

System Issues.

Who is going to be the primary agency responsible for managing care? Who will decide on the outcome measures? What should be done if there is a conflict between service providers and administrators? Will there be enough professionals to provide services to needy children, if funds are available? How will the needs of rural families be met? Who makes referrals? Who should monitor the referrals? What will happen if one professional group is not participating and/or cooperating? Who is responsible for managing the case? How can services be coordinated? Who will monitor the outcome? Who will make decisions about where to spend the resources? How will the need and priority for service be determined?

One important family system problem is that even trained personnel may not have a wealth of experience in dealing with very young children with special needs. If this is the case, how will training be provided? Another important question is, "How well are professionals prepared to work as teams, rather than as individuals?". Implementing Part H requires a team

approach in many cases. Does current professional preparation in all disciplines place enough emphasis on conferencing with other professionals so that the best information base is established? What kind of long-term commitment can the professional team make to the child and the family? Will the operating guidelines allow for long-term commitment? Or, will the child and family be "passed around" in a series of professional involvements in which professional practice may be very good, but the parents are left with feelings of distancing that frequently accompany dealing with a bureaucracy?

One of the problems with systems of care is that they tend to take on a life of their own. Clearly, potential systems problems that are recognized and confronted early are less likely to metamorphose into crises. For example, some of the families who will be eligible for service may be isolated from their extended family support network. How might a system be able to respond to this need? Can networking arrangements be structured for such families so that they receive support from other less-stressed families? What happens to Jennifer who is discharged from the hospital neo-natal clinic to her home in a rural area with few or non-existent services? Will there be a hot-line service for her parents to call in an emergency? Can training be provided for the parents in case of such an emergency so they can manage until they get to a hospital? Who will pay for the hot-line and/or the training?

Some system problems can be avoided if creative approach to finding solutions is encouraged, if mountains of red tape are reduced, if paper work does not take precedence over services, and if procedures are examined regularly to ensure that they are still functional and necessary. A critical question will be: *who will orchestrate existing services to create a whole delivery system that has no gaps?*

The economic realities of available services are rarely ideal. When resources are scarce, families are often forced to fit into the existing service delivery system. In an ideal world, the system would accommodate the child's needs. For example, suppose Jennifer requires routine

physical therapy at least twice a week, but the rural district in which she lives and where the early intervention service is located cannot afford a licensed physical therapist to provide the twice a week services. Instead, the administrators have recommended in-service training for the parents to provide basic remedial services to help Jennifer's motor development. The ethical question here is: *who should ensure that Jennifer gets proper services either by contracting in the private sector for services, or developing a consortium with other rural districts?*

Obviously some of the answers to these challenges can be found in professional experience. Successful professional practices by groups who have been dealing with children with developmental delays and children with disabilities have evolved over the years. The difference is that with the implementation of Part H, many groups will be involved -- not just one or two. How those groups assess the situation, plan together, interact (amongst themselves and with the family) to decide on the best way to proceed is critical to the success of the implementation policies.

## DEALING WITH VALUE CONFLICTS WITHIN A GROUP

This section discusses the problems of value conflicts occurring in a group. It also proposes some means of navigating through the discord that can emerge when self-interest is evident or values or are in conflict. The information is based on Gallagher's work of identifying individual value structures in a group.

Gallagher (1992) provides us with a clear example of how values may be perceived as being equally worthy -- depending on one's personal orientation. Regarding the sets of goals below, reasoned arguments could be made forcefully for either hierarchy, depending on one's political, professional or personal value orientation.

Table 1. Goals in conflict

| | HIERARCHY A | | HIERARCHY B |
|---|---|---|---|
| 1. | INDUSTRIAL DEVELOPMENT | 1. | PROVIDE INTERVENTION FOR YOUNG CHILDREN WITH HANDICAPPING CONDITIONS |
| 2. | REDUCE DEFICIT | 2. | HEALTH SERVICES FOR THE ELDERLY |
| 3. | AID TO PRIVATE SCHOOLS | 3. | MORE RESOURCES FOR PUBLIC SCHOOLS |
| 4. | BUILD MORE HIGHWAYS | 4. | AID FOR ENVIRONMENT |
| 5. | HELP YOUNG CHILDREN WITH HANDICAPPING CONDITIONS | 5. | INDUSTRIAL DEVELOPMENT |
| 6. | MORE AID TO PUBLIC SCHOOLS | 6. | REDUCE DEFICIT |

People who would support HIERARCHY A in Table 1 above could make the following argument: On a global scale, industrial development is the key to a country's economic success. If the United States is to provide any economic leadership for emerging democracies and third world countries, economic success must be a major priority in programs for the 21st Century. Failing to do well economically at home and in the international

marketplace will find us economically impoverished to the extent that we will never be able to support the social services necessary to look after the needy, the socially disadvantaged, and the elderly. To be economically competitive, we need to have a vast and well maintained highway system and give some support to private schools which often house the most economically advantaged students. These private schools are where some of the leaders of tomorrow are likely to be found. Aid to public schools ranks low on the priority list, not because they are unimportant, but because the problems are just too big to solve quickly enough to make an immediate impact on the economy. According to this viewpoint, the public schools need to find ways of using available resources in more productive ways.

People who would support Hierarchy B may have quite a different view of the problem. In their view (which they also see as economically driven), good business does not necessarily imply good economics -- that is if economics is defined as helping individuals reach their productive potential. These supporters may not understand why others have such difficulty realizing that prevention is less costly than the cure. Prevention includes helping people with disabilities, or people who are unable to fend for themselves, in ways that preclude the need for costly institutionalization. Hierarchy B supporters also believe that, for all its faults, public education is the major means to an informed citizenry which defines competent nationhood. According to these people, good public schools will produce economically self-sufficient graduates; people educated enough to realize the importance of environmental preservation and deficit reduction -- and with the wherewithal to work for it.

Individuals in the group who are polarized on the issues summoned by these scenarios are going to have to come to some agreement about their differing viewpoints if any progress is to be made. An important step in the process is to clarify the various positions of each group member and recognize them as worthy in their own right. Negative and closed-posture reactions to these very different viewpoints will simply result in individual entrenchment, and

either the group process will break down, or discontent will color all the rest of the process, rendering it less effective. Positive results are more likely if a tolerant atmosphere is maintained to allow members at opposite ends of the continuum of issues to discuss their beliefs without rancor.

Change of Views

How do people come to change views so dearly held? Gallagher suggests that personal involvement can make a big difference at this point. People who subscribe to Hierarchy A, for example, may change their minds if they actually meet children with disabilities to see how those children can develop with appropriate educational opportunities. These same people might even see a movie or television program about hungry children which will help to personalize what had previously been an abstract notion about deprived children. (One of the most powerful strategies lobbying groups can use is to have politicians engage in "walkabouts" in deprived neighborhoods for which the group is seeking funds.) Rarely can a thinking, caring adult come away from such face-to-face experiences with deprivation and not show a greater commitment to helping people with special needs. Members might consider a "field trip" to a situation demonstrating the kinds of needs they seek to meet. For those committed to Hierarchy B, a commitment to greater understanding of the economic aspects of school costs and benefits, and/or the relationship between business and school leavers' skills might affect the scope of their vision.

Obviously, some of the solutions proposed above cannot be implemented in the middle of a policy group discussion. They can, however, be part of a set of strategies for dealing with value conflicts. If, in an early stage of the policy meetings, value conflicts can be identified, group members can commit to trying one or more of the above ideas before they reconvene to discuss the issues further.

Another powerful tactic that can be used during a meeting is to find some common ground as a starting point for discussion. For example, if people who subscribe to Hierarchy A were asked point-blank, "*Do you think children should be made to suffer for the failures of their parents?*", or (putting it another way), "*Should children who are born into poverty remain there through no fault of their own*"?), they would likely answer, "*Of course not!*". This then shows another layer of the value structure that may not be apparent during an earlier discussion. It is at this second level of the value structure that agreement might be accomplished. So an important step in the group process is to find the "common ground" on which some accord can be reached. Unless this "second" layer of values is activated, the group discussion may degenerate into circular arguments in which positions are defended endlessly and discussion is circuitous, thus making progress impossible.

There are some indications that conflicting values are built into this legislation. Consider the following value statements: "THE PROFESSIONAL KNOWS BEST" and "THE FAMILY KNOWS BEST". Conflict occurs only in those those situations where the professional and the family are not in agreement. Where conflict exists, it is clear from the amount of available funds that the general public supports preparing qualified personnel to work with children and their families in complex medical, social, and educational issues. It is also clear that the legislation supports parental empowerment. The family is recognized as the ultimate decision maker when it comes to knowing what is best for the child. In other words, the policy makers for this legislation want the family to have executive control in the decision making process, but they also want the best professional advice available for those parents -- and the public seems willing to pay for it.

Other issues are not so clearly resolved at the national level and will have to be resolved at the state level instead. Examples of such values are: "CHILDREN WHO ARE MOST IN NEED SHOULD RECEIVE MOST OF THE LIMITED RESOURCES," versus"CHILDREN

WHO MIGHT BETTER **UTILIZE HELP** SHOULD RECEIVE MOST OF THE LIMITED RESOURCES." In some cases, this will be the same child. In other situations, there will be children who are more likely than others to benefit from services more quickly. If a choice has to be made, who should be the recipient? Resolving the possible conflict inherent in such opposing values is an example of the kinds of issues that the policy writing group will have to resolve as they write the guidelines for their state or region.

Other examples of guidelines that will have to be determined locally are definitions of "at risk", eligibility for treatment criteria, personnel preparation, the role of the family, finances, and the coordination of services. Such guidelines are subject not only to value conflicts within the group but also to problems of self-interest.

Problems of Self-Interest

What is meant by "self interest"? Self interest has both political and personal dimensions. The political dimension is based on motivations of power and control, whereas the personal dimension is driven more by emotions such as fear, anger, or love. In some contexts, self interest might appear to be similar to "vested interests". "Self interest", however, differs from vested interests in that self-interest is more likely to be based on what is "personally right" for that individual, whereas "vested interest" can be driven solely by political or professional motivations. Whatever it is called, the problem can have a devastating effect on the process of reaching consensus in any group.

Imagine an Interagency Coordinating Council (ICC) group in which some agency administrators are reluctant to participate in Part H in IDEA. They are fearful that the program will be poorly funded by their state, which has a history of holding a hard line in funding social programs. They suspect that the funds for social programs will not increase sufficiently for them to manage this new program in conjunction with programs for which they are already

responsible. The rest of the ICC members, who are not similarly affected, would see this as a clear case of self-interest.

The problem of self-interest is more than merely a different point of view. Self-interest is a common problem that can beset even the most well-intentioned group such that it can cause projects to founder, or at the very least never to reach potential. This is why it is critical that potential self-interests of the group members are recognized early in the process. It is usually easier to deal with self-interest before, rather than after, the fact. The scenario, on the following page (which is based on a true experience) is an example of what can happen when self-interest is recognized too late.

An enterprising mother of a severely retarded two year old wrote a matching fund grant for setting up intervention programs for preschoolers who were similarly afflicted. The grant was written specifically for children with the same condition as her daughter. There were no allowances made for children who did not fall within these parameters.

The mother used her considerable charisma and energy to involve private citizens and a few faculty members from the local state university to monitor the services rendered. So far so good. However, the chairman of the board was a highly motivated religious leader who believed firmly in the power of meditation and prayer. He had no real experience with children who were retarded but he had a good reputation for getting things done. He also had the ear of several influential local politicians. As chairman he had prepared a platform statement that was to be used to publicize the mission of the board. The statement included excerpts from religious scripts from several sources, but clearly the major thrust of the intervention would be religious intervention aimed at the level of the parents as opposed to more conventional practice.

The university faculty board members were appalled that state funds (even matching ones) were to be used in such a fashion and threatened to withdraw from the project. The chairman, the original grant writer, and several members of the board who were in agreement with him could not understand why anyone would be upset at what seemed to them to be a rational course of action. As one of them pointed out indignantly, "It wasn't as though we just used the Bible! We had other religious materials in there too. After all, we have the family's best interests in mind!" thereby missing the whole point of the discord.

The upshot of the whole brouhaha (which made fine press at a time of little news) was that the board lost the services of several fine professionals and the project suffered a loss of credibility as a result. This is a prime example of how self-interest--no matter how well-intentioned -- can disrupt a potentially powerful service.

Table 2. Determination of interests

| |
|---|
| • *In this case, at least two sets of interests **were not** served:*<br><br>- the children who were excluded initially from the grant because of the tight restrictions written into it<br>- children who were admitted to the program but did not receive adequate care due to conflict of professional interests<br>- a potential clientele for whom services were desperately needed but who were left out in the cold when the grant was not refunded.<br><br>• *Whose interests **were served**? Those of:*<br><br>- the grant-writer's daughter who was the beneficiary of many services<br>- the original grant-writer who maneuvered the state into a dead-end project<br>- the religious leader who was able to manipulate the situation to suit specific religious ends<br>- the preschoolers who were served during the reign of the first board and received qualified care at during the first part of the project. |

The previous scenario (Table 2) shows what can happen when different agendas are not attended to from the beginning of a project. In this case (based on a true story), self-interest derailed a very promising project. In this scenario, it is clear that the main source of self-interest was the mother. She not only wrote the grant, but also chose the chairman of the board. It might have been possible to deal with the mother's self-interest had she discussed the idea with another professional before she submitted the grant. Perhaps at that time, she could have been helped to understand that expanding the services to other children would not necessarily deprive her own daughter of much needed services. At the point of choosing the board members, some input about the possible problems of working with a clearly proselytizing member of a church might have been helpful. This scenario makes it obvious that self-interest should be identified early in the process or that process could be derailed.

These examples demonstrate that self-interest can occur at multiple levels. Group members who have overwhelming self-interest tend to have a limited vision of the problem and therefore a limited view of the potential solutions.

Sometimes what appears to be self-interest is really a result of how people think about problems in general. The research findings on learning styles in the past decade indicate that there are some people whose thinking processes cause them to move rapidly toward solutions in a linear way. Other people, however, might think more globally about the problem and need far more information before considering possible solutions. Most of us fall somewhere between these two extremes in thought processes. Linear thinkers get impatient with the more global thinkers because it seems to take them forever to make decisions. Global thinkers are uncomfortable with what they perceive as pressure to consider solutions when, in their view, the problem has not been properly investigated. Linear thinkers with strong feelings about certain aspects of Part H in IDEA who are members of policy writing groups may come to the group process with clearly delineated agendas. Procedures outlined in the next component might be of help in dealing with the disparate ways in which people think. These procedures also could assist with the problem of identifying and solving problems that arise from self-interest.

# ETHICAL DECISION-MAKING

Moral dilemmas inevitably arise when laws intended to serve a public good have to be interpreted to meet individual needs. The procedures and protocols suggested in this component are based partly on Bryant Kendrick's Ethical Method model and are designed for the purpose of resolving conflicts arising from value differences within groups. Vignettes exemplify some of the problems that can beset any group of well-intentioned individuals struggling with ethical issues. The first part of the component explores when an Ethical Method is needed and how it might help a policy writing group. The last section demonstrates how the same method could be used at the local level to implement those policies.

## When is an Ethical Method Needed?

The need for an ethical method to help individuals or groups make moral decisions arises when four co-incident conditions occur. The first condition involves recognizing that the choice we are to make requires using values to determine our options. An ethical method helps to identify which values are involved and guides in the evaluation of the relative merit of those values with regard to different options.

The second condition involves the need to render a decision that is more than merely a reflection of our own personal beliefs. Usually we act on this condition when we are aware that our choices affect the lives of others. Ethical decisions are especially critical in professional actions and in making policy decisions that affect the lives of others. Because the option ultimately selected may have a profound effect on others' lives, the process that lays the foundation for the decision-making must be more rigorous than the process used in making personal decisions. Decisions that affect others need to be based on thinking that is free from prejudice, personal benefit, and factual error. An ethical method helps put some distance

between our existing preferences and the choices we are to make. It helps us craft a set of reasons for our choices that are based on a thorough review of the facts at our disposal and thoughtful consideration of the values involved--reasons that may appeal to our common rationality--so that any individual taking the time to follow the ideas developed might also be convinced that the choice was a reasonable one.

The third condition signaling the need for an ethical method is the confusion over how to make moral choices that result from cultural pluralism. In our multi-cultural society there are many moral positions--some grounded in deeply-held religious beliefs, others in non-theistic philosophical theories of human existence, many, maybe even most, just lived out and not thought out in any particular depth. While such diversity is celebrated when we focus on the dynamism of our culture, it is sometimes seen as a drawback when moral consensus is sought as a basis for action. Therefore, it is unrealistic to expect that any group of persons will automatically achieve consensus on significant moral questions.

The fourth condition involves recognizing that an opportunity exists to shape events so that decisions are driven by considerations of what "ought" to be as opposed to merely what "is". All too frequently, the "what is" tends to be the result of political forces reflecting the power of various social groups or years of compromises that have distorted the purpose or the goal. Part H affords society the opportunity to move toward "what ought to be".

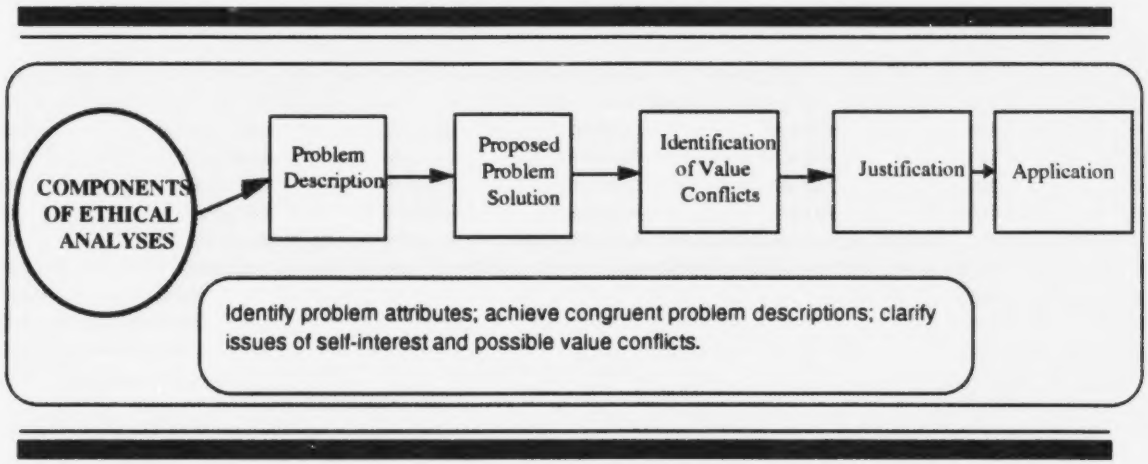
<u>How will the Ethical Method help?</u>

An ethical method will assist the members of such a group to clarify the various positions each holds and to see how those positions are logically connected or juxtaposed, both internally and in relation to the positions of other group members. While individuals are free to hold a variety of beliefs, an ethical method will provide a mechanism for establishing standards of consistency and clarity in the expression their ideas. In our language, the same word can be used to express various shades of meaning. For example the word "poor" can mean

"impoverished" or "of low quality" depending on the context in which it is used. It is important that persons constructing an ethical method of analysis of an issue be aware of the wide range of meanings important terms might have. Clearly stating these meanings and selecting which ones will be used is a necessary step in achieving consistency.

Clarity is enhanced when assumptions, facts, and value concepts are openly stated to minimize ambiguity. We become comfortable with our various professional terminologies and can communicate easily with people within our own professions. When we use that terminology in a public forum such as a policy writing or policy implementing group, we are often perceived as using "jargon". Finding ways to achieve clarity without resorting to jargon is not a simple task. After all, professional terminology is usually generated to increase precision in the language--not confound it! An ethical method helps bring our thinking into the open for public scrutiny and discussion so that consideration of these issues can benefit from a wide review.

Figure 3. Components of the ethical method


COMPONENTS OF ETHICAL ANALYSES
Problem Description
Proposed Problem Solution
Identification of Value Conflicts
Justification
Application
Identify problem attributes; achieve congruent problem descriptions; clarify issues of self-interest and possible value conflicts.

This chart shows the five steps of Kendrick's Ethical Method: Problem Description, Proposing Solution Alternatives, Identification of Value Conflicts, Justification and Application. The next section describes some protocol materials and then discusses how policy groups might make use of an ethical method and the protocols suggested. It is important to state here that the protocols outlined here are simply suggestions. Groups should feel free to modify the forms to meet their individual needs or develop their own forms entirely. In addition, master forms, which can be copied for use with groups, are available in Appendix B.

Problem Description Phase

Policy groups can use this phase to identify the policy problems they anticipate encountering in their state or region. Problem Description involves a complete description of a problem together with an identification of related problems and other professional concerns. The form also provides a space for listing further information necessary to begin seeking solutions.

The problem description phase is the foundation for the rest of the policy-writing process; therefore it must be thoroughly developed. In an hypothetical scenario, suppose a policy group decides that it should define the term "at risk" as it applies to their region. As the discussion ensues, it soon becomes obvious that there is no consensus in the group about such a definition. Two members pose an extremely broad definition, several others want to narrow the range. This is a time when the Ethical Method could be helpful. A form similar to the Problem Description form on the next page could be used for identifying the information base:

## PROBLEM DESCRIPTION FORM

**Date:**_____
**Evaluator's position:** _____

**Brief description of specific problem:**

_____

_____

_____

**Related problems (current):**

_____

_____

**Professional Concerns:**

_____

_____

**Needed information:**

_____

_____

The "**needed information**" might include data from the state about the number of babies who were born to drug-abusing mothers in the previous year, the number of infants who were premature and/or of low birth-weight, the number of babies born to single teenage mothers, the number of families with very young children who were on food stamps to name only a few sources of the data. Group members can describe their definitions of "at risk" with supporting rationales and then compare descriptions.

The proposed problems description form separates "**related problems**" from the "**specific problem**". Groups may decide to dispense with this category and simply list all aspects of the problems under the "specific" category. For example, the specific problem in defining "at risk" might be simply getting everyone to agree on the term. Whereas "**related**

**problems**" might include costs of being too inclusive. "**Needed information**" could include finding out how other regions with similar demographics and budgetary problems have determined who is considered "at risk". Another example is, if only national data are available, "regional data sources" could be listed in the "**needed information**" section.

Disagreements are likely to arise at this stage because some members may not be privy to all the information. In addition, policy problems often overlap. If the term "at risk" is viewed as synonymous with "eligibility for treatment" some group members may prefer to narrow the definition rather than face possibly more difficult decisions about what the criteria are for eligibility for treatment.

If conflicts are anticipated, the likelihood is that they will arise in the problem description phase. It might be helpful to begin to list the conflicts among the group early in the process on a separate form. These conflicts may be either in their own biases or in known positions of other group members. Listing possible conflicts early in the discussion could save time and energy in that others' philosophical positions would be acknowledged.

The problem description phase, therefore, accomplishes three ends. First, it serves to separate problem components. Second, it encourages open communication because members are more likely to write down more of their relevant knowledge and expertise individually, than when there is only verbal discussion among the whole group. Third, it identifies at an early stage possible conflicts existing either within the group, or with other policies.

Once the available information has been gathered and conflicts about the information identified--even if not entirely resolved--a master copy can be generated from the revised individual descriptions so that the whole group is working from the same information base. At that point it is time to seek some solution alternatives.

Proposing Solution Alternatives

Budgetary and personnel constraints at both state and local levels will require some innovative responses to problems. Innovation and creativity depend equally on information and the ability to view things from different angles. Brainstorming for generating solutions is a strategy used by numerous professional and business groups who are confronted with the task of making difficult decisions and/or finding novel solutions to problems. The policy group could brainstorm possible solutions to the problem of too broad a definition of "at risk" that was identified as a problem. The **Solution Alternatives** form below is designed to assist in that aspect of the task. Group members should try to write down all the possible solutions to the problem before moving to the "**Necessary Steps**" part (describing the steps to apply each alternative), and "**Other Considerations**" (listing potential problems). While working on these parts, it is important not get too caught up in details. It is better to simply outline the steps and mention the most pressing problems for each solution. It is possible that a particular solution may be discarded after discussion among the whole group. Forms should be provided for as many separate solutions as the members propose.

**SOLUTION ALTERNATIVES**

**Solution:**_____

**Necessary Steps for implementation:**_____

_____

_____

_____

**Other Considerations:**_____

_____

After everyone has completed their forms, a master list of all the various solution alternatives can then be created so that the whole group can view all possible solutions generated individually. Using this two-step process for generating the list of solutions may seem cumbersome at first but people who are new to the group, or who feel they are not as knowledgeable as some other members, are more likely to express their ideas if they have an opportunity to consider them privately first.

Once the master list is generated for all to consider, there are several things that can happen:

1. Similar ideas for solutions can be clustered together thus reducing redundancy.
2. Also, "Necessary Steps" and "Other Considerations" can be filled out in greater depth to see if there are unintended "side effects" of a particular solution that may generate other problems.
3. At this point only redundant solutions should be discarded.
4. The remaining solutions are discussed and it is here that the process can get bogged down in value-laden debates.

The Justification and Application phases can be written later. If the solution is arrived at by consensus or unanimous vote, perhaps no justification needs to be written. If the solutions are arrived at with some contention, however, then a justification probably should be articulated, if for no other reason than to provide documentation for posterity.

If it is clear by step #3 in the process outlined above that there is disagreement about a solution, it may be because people hold to very different visions of what is important. These visions are usually enshrined in religious traditions or in strongly-held philosophical positions.

Applying the Ethical Method to a Case

In this last section, we will briefly review the protocols that were outlined at the beginning of this component and show how they might become part of a set of procedures for implementing the policies at a local level.The following vignette is an example of the kind of implementation situation that policies will have to be written for at a local level. In this scenario, in which self-interest on at least two of the participants is evident, the way in which policies are written could affect the outcome and eventually the well-being of the target child.

Hillary Michaels has an 18 month old daughter, Caitlin, who has cerebral palsy with a related seizure syndrome. Caitlin is entering that stage of her development where she needs more care and more constant therapy. Hillary wants to place Caitlin in a foster home so that she (Hillary) can go back to university to complete her bachelor's degree in marketing. Hillary has been divorced from Peter, Caitlin's father for a year and feels resentful about having to shoulder the entire load of Caitlin's care. Peter visits Caitlin at Hillary's apartment (sometimes babysitting Caitlin for a whole day at the weekend), but never takes her back to his own apartment where he lives with his new wife who is expecting her first child. Peter pays child support for Caitlin but Hillary works part time in the evenings as a waitress to supplement her income. Her co-workers, who constitute her main support group, can offer her little but sympathetic ears. Her neighbors nearly all work and those who do not are unwilling to assume responsibility for a child with cerebral palsy.

The social worker at the center where Hillary takes Caitlin for therapy has convened a group meeting with Hillary, Peter, Caitlin's doctor and herself. Several ideas for managing Caitlin are explored to try to find acceptable solutions to the problem, but Hillary remains adamant in her insistence that she cannot continue to care for Caitlin and work toward her degree at the same time. She claims that the quicker she finishes her degree, the sooner she will be able to provide a decent life for herself and her child. She intends to bring the child home and pay for in-home child care once she has a good job.

Peter's new wife refuses to assume the responsibility of Caitlin's care. She is afraid that she will be "stuck with Caitlin" forever (her words). Peter does not want Hillary placed in a foster home at this age. Hillary vents her anger ostensibly at Peter during the meeting. In listening to Hillary, the social worker becomes concerned that unless some way can be found to neutralize Hillary's frustration, Caitlin may be at risk for some possible abuse. The physician is concerned about Caitlin being removed from his care.

Although this example is a clinical case, and the decisions will be clinical decisions, it is exactly these kinds of scenarios that will have to be considered when the policy writing group gathers to forge the policies for their state or region. The completed protocols on the next few pages show how the ethical method might be used to find some common ground among the participants in this scenario:

## PROBLEM DESCRIPTION FORM

**Clients' Names:** Hillary Michaels, Caitlin Michaels (daughter) Date: 1/20/93
**Evaluator's position:** Caitlin's mother

**Brief description of specific problem:**
I want to return to school but cannot find adequate child care. Peter is not willing to provide more than current financial support. I can't afford to pay for more care than I am doing now. Peter should be willing to take more responsibility. If I don't return to school soon, I will be too old to obtain a decent start in the market place to ensure Caitlin and me a good life.

**Related problems (current):**

Peter's new wife is jealous of the time he has to spend with Caitlin. She does not want to have anything to do with Caitlin. Very possessive. I will need time to study beyond just class time. Caitlin should have the best care. I have no-one to turn to.

**Professional Concerns:**

---

**Needed information:**

---

## PROBLEM DESCRIPTION FORM

**Clients' Names:** Caitlin Michaels (daughter) Date: 1/20/93
**Evaluator's position:** Father

**Brief description of specific problem:**

Ex-wife wants to give Caitlin up. Says she wants to return to school but really this is just an excuse to get out of her responsibilities as a mother. I think she is tired of being a mother.

**Related problems (current):**

Julie is pregnant and anxious about my relationships with my other family. She is giving me a hard time about spending any more time with Caitlin than I do now. I love Caitlin, but it is not fair to my wife to expect her to look after Caitlin with her condition. The present arguments are causing us trouble at home. I can't afford any more money than I'm giving now.

**Professional Concerns:**

I think Caitlin needs full-time care (like any two-year old) and I don't believe she'll get the same quality care in a stranger's home. I think Hillary needs professional help.

**Needed information:**

Can Hillary be tested psychologically without charge?

## PROBLEM DESCRIPTION FORM

**Clients' Names:** Michaels Family Date: 1/20/93
**Evaluator's position:** Social worker

**Brief description of specific problem:**

Mother and father of child with cerebral palsy and related seizure condition cannot agree on how to care for child while mother returns to school to earn a degree.

**Related problems (current):**
There are financial problems for both parents. Father has remarried and is starting a new family. Second wife does not wish to be involved in Caitlin's care. Mother seems to have been house-bound since baby was born or working for additional income.

**Professional Concerns:**
Am concerned about potential abuse if Hillary is not provided some respite or ways to meet her own needs and goals. Am also concerned that Caitlin may lose out in the family constellation if separated from parents. Can we find a good group home near current family location?
**Needed information:**

Have we exhausted all resources for financial aid for mother to return to school? Are there any women's groups who would be willing to take on Hillary and/or Caitlin?
What time lines are we looking at? Will Hillary want to do graduate work later?

## PROBLEM DESCRIPTION FORM

**Clients' Names:** Peter Michaels, Hillary Michaels, Caitlin Michaels (daughter)
**Evaluator's position:** Pediatrician

**Brief description of specific problem:**

Single mother with separated father (pays child support). Child has cerebral palsy and related seizure condition. Mother wishes to return to school but cannot find adequate child care. Father cannot provide more than current financial support. Child does not need skilled nursing care.

**Related problems (current):**

System does not provide custodial care for child or respite services for parents.
Mother has little support network. Caitlin's grandmother babysits but is unavailable during the day. Father is starting another family. Unwilling (unable?) to provide more financial support. Mother's financial condition also marginal.

**Professional Concerns:**
Child has good standard of current care. Unless similar level of care can be ensured, quality of life may be compromised.
Will Caitlin continue to be under my care, or will she be transferred to another doctor?

**Needed information:**
What other day care possibilities exist in the same neighborhood? How long will Mother have to attend school to complete degree? Can some course work be taken at night to allow grandmother to continue to offer services? What length of time can we anticipate that Caitlin will need supplementary care?

It is clear that the way in which the various players in this scenario complete the problem description forms reflects how differently they view the problem. There are even differences in the way they identify the client! Unlike the two professionals, Hillary and Peter

no longer see themselves as a family unit. Peter sees Caitlin as the client while Hillary views both herself and Caitlin being the clients. It's possible that even the doctor does not see them as a "family" even though he has written all of their names as clients.

The "brief description" of the problem sheds more light on how each sees the problem from a different viewpoint. The professionals are more objective and probably clearer in their perspective of the real problem than are Peter and Hillary. The latter two see the problem through the filters of their own needs. Although Hillary's motive seems reasonable in her own eyes, her unwillingness to consider caring for her daughter at home while she completes her degree is a clear case of self-interest. The father's self-interest is even clearer in his unwillingness to assume more responsibility for Caitlin. He then resorts to blaming Hillary for reneging on her maternal responsibilities. He is at a loss to understand why any good mother would want to abrogate her care-giving responsibilities, hence his suggestion that Hillary receive some professional help.

When the information in the various problem description forms is shared, it provides an excellent opportunity for the professionals to encourage Hillary and Peter to discuss the problem more deeply from their perspective. Hillary starts by asserting that her pregnancy with Caitlin was the major impetus for her to marry Peter and drop out of university in her junior year. In retrospect, she now regrets this because at the age of twenty-three she finds herself with a baby who is very different from what she expected, no real support other than her mother, a physically demanding job that pays poorly, and little or no social life.

Peter describes the problem quite differently. He insists that the problem could be solved if only Hillary would agree to assume the responsibilities of a "good mother". From his perspective he "tried to do the right thing" by marrying Hillary who changed from a fun-loving young teenager into a bitter woman who now is more interested in fulfilling her own needs. In

Peter's view, women who have young children should find fulfillment in the motherhood role and not seek further education until the children are much older.

The professionals involved in this situation probably have their work cut out to help both Hillary and Peter realize that some accommodation of their career goals and lifestyles may be in the best interest of their daughter while she is so young. The antipathy between Peter and Hillary about the divorce and the resentment Hillary feels for Peter's expectant wife may be some of the underlying issues that will have to be recognized in this situation.

What are the various roles of the professionals in this case? One role might be helping the major players look at the problem from different angles. For example, in the previous scenario, Hillary might describe the problems of caring for Caitlin differently than would a child development specialist. Where Hillary might emphasize the negative aspects of her frustration in responding to what appears to her as Caitlin's need for constant attention, a development specialist describes more gains in alertness and attention span over several months.

Another role will be to make Hillary and Peter aware of available care and treatment options. In a family systems model the strengths of the family are considered when decisions about treatment are made. It is clear that there are several value conflicts that have to be resolved before any further progress is possible. Each parent's view of what constitutes parental responsibility differs markedly. At this point, it is less important to get Peter and Hillary to change their viewpoints about parental roles than it is to agree on the description of the problem of Caitlin's care in practical terms without making judgements about whose job it is to do what.

In the "**professional concerns**" section, Hillary has left this part blank. Peter, however, seems to have interpreted the terms in light of his own needs when he asks, "how can a professional help **me** in this situation?" In discussing this section of the problem

description form, the professionals can share their views of the immediate situation and take the opportunity to share their knowledge of how Caitlin's needs will change as she grows older. At this point, Peter may begin to realize that further education for Hillary is not a luxury, but a necessity.

In the Caitlin's case, self-interest was identified as a major problem. The respective self-interests may become apparent to both Hillary and Peter through the task of completing the Problem Description form. It is possible that forcing the protagonists to write their concerns down will help to crystallize the problem for both Peter and Hillary. Writing one's thoughts frequently helps to clarify them. The completed forms would result in a description of the problem from everyone's viewpoint.

If self-interest can be revealed through the use of the problem description form or similar mechanism, and if all the professionals involved have described the problem fully from their viewpoints, the discussion can move on to the "Identifying Value conflicts" phase at this point before looking at proposed solutions. In the case of Hillary, Peter and Caitlin, it is clear that there are several value conflicts that have to be resolved before any further progress is possible. Each parent's view of what constitutes parental responsibility differs markedly. Here, there is less to be gained in circuitous arguments about which parent is bearing most of the responsibility than there is to trying to reach agreement about what Caitlin needs and how those needs can be met in a reasonable manner.

No single way to resolve value conflicts exists. In some cases, this can be achieved by dealing with such conflicts through discussion. Another way would be to list those beliefs that everyone can agree upon clearly on a sheet of paper. For example, in Caitlin's case, the one belief that all parties might agree to would be that Caitlin must continue to receive good care. Another might be that Hillary must be able to obtain more education or training to increase her employment opportunities. Although Peter and Hillary hold different views about

how these two beliefs should actualized, the beliefs at least are congruent. This will provide a good starting point for moving on to the Solution Alternatives component.

From the previous discussion it sounds as though once the air is cleared regarding value conflicts, the problem is solved--never to raise its disruptive head again! Life being what it is, we are likely to encounter other value conflicts in the next two phases of the decision-making process. However, the conflicts may be resolved more easily if meaningful discussions have taken place earlier.

Solution Alternatives

This form is one that should be completed by consensus. This does not mean that all proposed solutions have to be agreed upon immediately. Again, simply writing them down will help to clarify the issues and allow some merging of solutions when appropriate. With the Michaels family, several solution scenarios could be proposed. This part of the process is to allow participants to "try on" alternative solutions to anticipate more clearly new problems that might arise. Preparing the solution alternatives should also help to neutralize some of the dissonance within the group because the focus has moved to finding solutions rather than dwelling on problems.

Two of the possible solutions for the Michaels family are outlined on the following page. These alternatives were arrived at through discussion among all the participants.

**SOLUTION ALTERNATIVES #1**

**Solution:**Hillary will apply for admission to the university and enroll as a part-time student for the first semester. She will take one evening course. Peter will pay for_ a qualified babysitter for ten hours a week throughout the semester. This will allow Hillary some class and library time. If successful in this course, she can apply for financial aid to go to school full-time in the following semester.

**Necessary Steps for implementation:** Find a qualified sitter.

**Other Considerations:**Peter may have to get a part-time job to pay the extra costs. This is not a long-term solution. Full-time course work will require more funds for Caitlin's care if she stays in the home.

**SOLUTION ALTERNATIVES #2**

**Solution:**Hillary waits for another year before trying to go back to school. She will find a second part-time job that will improve her financial status and Peter will contribute money for a qualified sitter for Caitlin while Hillary works. Peter will also babysit two whole weekend days and evenings every other week to permit Hillary more social opportunities.

**Necessary Steps for implementation:**Find a qualified sitter.

**Other Considerations:** Peter may still have to get a part-time job.

Obviously, neither of these solutions are what Peter and Hillary had in mind when the problem was first presented to the ICC. The first solution, however, is one that Hillary could

probably live with. Enrolling in any university takes some time and her involvement in course work will begin to move her in the direction that she wishes to go. The second solution addresses other more subtle aspects of Hillary's concerns. Part of Hillary's desperate need for returning to school may lie in her feeling trapped both financially and socially. By increasing Peter's responsibilities with Caitlin, Hillary will be able to take advantage of the extra time to earn more money and have some time for herself.

Both solutions meet one of Peter's concerns: that of keeping Caitlin at home. Both solutions, however, will result in Peter paying more money and/or increasing time spent in meeting his responsibilities as a father. This factor may impact his current marriage negatively so further professional involvement with Peter and his wife may become necessary. The increased financial responsibility for Peter may not last more than two to three years at which time, Hillary will likely be in a better financial position herself. In the mean time, the proposed solutions buy a little time for all concerned. Caitlin will not be moved to a group home; Hillary can ease into the pressure of course work more gradually, and Peter is not faced with paying for a full-time babysitter immediately. The professionals will have more time to seek resources to help this family meet its various needs while ensuring that Caitlin will continue to receive the therapy she needs and will continue to be cared for adequately at home.. It's also possible that Caitlin's seizures may become less frequent as she gets older.

In a situation like this, several solutions may have to be proposed before the right one is formulated. Peter and Hillary's philosophical positions were so polarized that the final solution may not fully meet either of their initial desires. This is true of many problems that IFPSs deal with. Consensus is the goal and the procedures outlined should help to accomplish that goal.

Justification and Application

These two phases are combined in this component because it's difficult to consider one without the other. In fact, ease or difficulty of application might be factors in the justification of one or more possible solutions. In the Michaels case, both solutions hinge on finding a "qualified sitter". The professionals involved will have to agree on what constitutes a "qualified sitter" and if such a person cannot be found, taking Caitlin to a suitable group home for one or two days a week may have to be considered.

In the case of an ICC group using these protocols, the process is similar. When all the possible solutions have been listed, each solution can be subjected to reasoned analysis for adoption. Solutions can be clustered. Perhaps a frequency count could be taken. Frequency counts indicate which are "popular" or "unpopular" solutions. Each solution or cluster of solutions needs to have a fair hearing before it is "disqualified". Unpopular solutions need not be dispensed with too hastily because innovation is not always immediately well-received.

If a proposed solution implies a number other potential problems (evident in "**other considerations**"), then that solution might get moved further down the priority order. If, in addition to problems, there will be difficulty in implementing the solution, it will likely find itself close to the bottom of the list. At this stage, regardless of how the group works, it needs to have access to the information at the same time. Newsprint sheets that can be pasted up on a wall are valuable tools at this point.

Whatever procedure is used, there are similar steps to be taken:

1. Describe the problem clearly to the point where the group achieves consensus on "the problem"
2. Identify potential value conflicts:
    a. first look at possible self interests within the group
    b. then consider value conflicts that arose in the

problem description phase

3. Generate several possible solutions
4. Choose the solution that meets any further criteria established by the group.

No time frame is suggested because each situation is quite different in its complexity. Some problems will be reasonably simple, many will be quite complex. It would probably be very helpful if policy groups could assemble a "case book" in which examples are drawn from professionals' case-loads and subjected to the policies that are formulated. Such a case book would be a good reference for interpreting and implementing policies at the local level.

In a family systems model, it is conceivable that these processes could be revisited at various times for the same family. For example, in the case of Caitlin, it's possible that after Hillary achieves her undergraduate degree, she is offered a job that requires her to travel away from home two or three times a month. Although the professionals involved were able to work out a solution for Hillary to manage Caitlin while she was studying, the traveling will present a different set of problems.

Policy Implications for this case

How can policies be written so that families like Caitlin, Hillary, and Peter can be assured of fair and equitable treatment under the law? Who is really the client in this case? Hillary, who has many unmet needs? Peter, who is trying to build a new life for himself? Or Caitlin, who is trying to survive in the cross-fire of her parents' anger? All three are "clients" and have needs. All three constitute a "family" of sorts.

It is suggested that policies should be written such that *a wide variety of family configurations are recognized.* In today's world, the nuclear family should not drive policy. Caitlin is part of a family cluster that includes her maternal grandmother and her father's new

wife. Policies that *include clear statements about working with the family, versus focusing only on the child,* will help to maintain a family systems view in the implementation phase.

Can the use of an ethical method like Kendrick's constitute part of the problem-solving methodology that the policies outline? Policies that *encompass the use of systematic procedures for identifying self-interest and accompanying value conflicts* will go a long way to helping local ICC's implement the guidelines reasonably.

In the case of Hillary, Caitlin and Peter, the professionals' effectiveness will be greater if *policies exist that legitimize the various roles they probably have to play.*

## Conclusion

The procedures suggested in this handbook are not overly difficult to use. Nor are they as time-consuming to implement as they are to read about! In the long run, systematic procedures probably save time in that situations will not have to be revisited as often had such procedures, not been employed.

Finally, the use of the family systems model as the basic premise for policy-writing that is suggested in this handbook provides a consistent foundation for the proposed practices. It is the hope of the contributing authors that this will be a helpful tool in formulating and writing guidelines for implementing Part H in IDEA which has the potential to make such a difference in the lives of so many children and their families.

Appendix A

**Annotated Bibliography**

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Here are notions of how to generate the energy and confidence to successfully advocate for one's own handicapped child.

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The authors are all professionals who somehow work with handicapped children and their families, as well as being themselves parents of handicapped children. As one would expect, they epitomize the need for dialogue between these two roles, or groups of people.

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Case-study research and participant-observation data collection are used to examine therole of policy analyst within the process of implementation.

White, J. D. (1982). Public Policy Analysis: Reason, Method, and Praxis. George Washington University, 42: 545-A.

Challenges the narrow and distorted view of reason in the practice of policy analysis, as well as the ability of standard methods of policy analysis to understand particularly the ethical, aesthetic, and crisis dimensions of society.

Wildavsky, A. (1979). Speaking Truth to Power: The Art and Craft of Policy Analysis. Boston: Little Brown.

A comprehensive and highly useful discussion of the role of policy analyst, and some notion of how the practice might ideally occur.

Zetterbaum, M. (1977). Equality and human need. The American Political Science Review, 71, 983-98.

Raises the question of value particularly that of equality as relating to, or deriving from, human need.

Appendix B

**Sample Forms**

(for xerox purposes)

## PROBLEM DESCRIPTION FORM

**Date:**_____

**Evaluator's position:** _____

**Brief description of specific problem:**

_____

_____

_____

_____

**Related problems (current):**

_____

_____

_____

**Professional Concerns:**

_____

_____

_____

**Needed information:**

_____

_____

## SOLUTION ALTERNATIVES

**Solution:**_____

**Necessary Steps for implementation:**_____

**Other Considerations:**_____